Considering Culture in Autism Screening, Diagnosis and Treatment

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Plan

- 1- Background; Review of what we currently know
- 2- Definitions of Autism and Autism Spectrum Disorders
- 3-Pitfalls of testing in culturally diverse families
- 4-Autism screening, diagnosis tools and limitations
- 5-Implications for treatment and referrals
- 6-”Considering Culture in Autism Screening and Diagnosis” Kit project
- 7- Other resources

1 out of every 88

children in the United States has

AUTISM

Importance

- Diagnosis is behavioral, dependent on history and observation
- Diagnosis and intervention require navigation of complex systems and highly trained professionals who can communicate effectively with child & family
- Successful intervention must include family involvement

1- Background: What do we know now?

- In U.S., culturally and linguistically diverse (CLD) population is rapidly growing
- In MA, 16.3% students first language not English
- Not a lot of research in ASD in CLD populations
- Some research on racial/ethnic disparities

Research Challenges

- Logistics
- Access and population involvement
- Stigma
- Mistrust of research

Epidemiology-Race/Ethnicity

Mandell et al (2009) examined racial/ethnic disparities in ASD identification through CDC ADDM

- Results
  - 58% meeting ASD case definition had this documented in records
  - Black, Hispanic and "other" race/ethnicity children less likely to have an ASD classification
- Limitations
  - Case identification strategy relied on secondary data
  - Data on some variables unavailable for portion of sample

Epidemiology-Race/Ethnicity

- Liptak et al (2008) used nationally representative sample to evaluate prevalence of autism and access to services in underserved populations
- Households surveyed in National Survey of Children's Health (telephone survey by CDC 2003-04)

- Results
  - Latinos had a lower prevalence rate compared to non-Latinos
  - Severity of autism (reported by parents) higher amongst Latinos

Epidemiology-Race/Ethnicity

- Most recent ADDM data
- Identified ASD prevalence in 8 year-olds by race/ethnicity
  - White>Black>Hispanic
- However, percent change 2002-2008

  Hispanic children 110%

  >Black children 91%

  >White children 70%

Epidemiology-Immigrant populations

- No national surveys on ASD prevalence among recent immigrants to US
- Begeer 2009, found culturally and linguistically diverse children were less likely to be referred for ASD evaluation
- Recent analysis of 2007 National Survey of Children's Health
  - Much lower ASD prevalence for Hispanic children with foreign-born parents compared to Hispanic children with US-born parents

Early Identification

- In analysis of 10 birth cohorts from CA, parental race and maternal immigrant status, as well as lower education, negatively influenced age of ASD diagnosis (Fountain, 2011)




Average age of diagnosis

- Autistic Disorder:
  4 years, 0 months
- ASD/PDD:
  4 years, 5 months
- Asperger syndrome:
  6 years, 3 months

Special populations

Prevalence increases - race/ethnicity

- White, non-Hispanic, 70%
  - 12 per 1,000
- Black, non-Hispanic, 91%
  - 10.2 per 1,000
- Hispanic, 110%
  - 7.9 per 1,000

Identification of ASDs in MA

- 1/108 in 2006 birth cohort
- Average age of diagnosis in EI populations: 25.6 months
- Racial/ethnic differences in early diagnosis substantially decreased from 2001-2005
- Later diagnosis
- Disparity challenges:
  - Primary language not English;
  - foreign born mothers

Rising to the Challenge

- The American Academy of Pediatrics (AAP) recommends ongoing surveillance and ASD-specific screening at 18 and 24 months or whenever there is concern.
- Autism screeners, such as the M-CHAT, are more accurate when used in conjunction with clinical judgment.
- *Children with autism from minority backgrounds are often diagnosed at a later age than other children*
- The concepts of screening, early identification and early intervention may be unfamiliar for families from diverse background.
- *For many families, these concepts are culturally bound and they may perceive that their children will be stigmatized in their communities by participating in these practices.*

2- Autism Spectrum Disorders (ASD) Definitions

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What are ASD?

- **DSM-IV-TR:**
- **PDD (Pervasive Developmental Disorders)**
  - **Autism**
  - **PDD,NOS**
  - **Asperger Syndrome**
  - **Rett Syndrome**
  - **Childhood Disintegrative Disorder**

Autism Spectrum Disorders (ASD)

Definitions from the DSM-IV

DSM-IV :

1) Qualitative impairment in social interaction

2) Qualitative impairment in communication

3) Restricted, repetitive and stereotyped patterns of behavior, interests and activities

4) Onset in the first 3 years of age

Remember: In younger kids, presentation may be different. DSM-V in the works.

3- Pitfalls of current assessment approaches with diverse populations

What is culture?

- Set of learned traditions and living styles shared by members of a society: thinking, feeling and behaving.

- Different dimensions:

  1- Internal, subjective or psychological representation of culture: thinking, feeling, knowledge, values, attitudes, and beliefs

  2- Behavioral dimension: ways we relate with others, ways we behave in different context, festivities

  3- Cultural elements: physical elements characteristics of that group: symbolic clothes, ornaments, houses etc..

Culture: Defining Elements

- Cultural variables affecting cognitive testing becoming more and more evident:

- Values
  - Human nature
  - Man-nature relationship
  - Time orientation
  - Activity
  - Relational

Culture: Defining Elements

- Attitudes and Beliefs
  - Ideas and thoughts common that govern interaction
  - Possess emotional content
  - “Cultural transmission”

- Interpersonal behavior: Three universal dimensions to interpret interpersonal behavior:
  - Association/Dissociation (affiliation)
  - Superordination/Subordination (Dominance)
  - Intimacy/Formality

Psychometric Cognitive Testing

- Cultural concept and developed within a specific cultural context: Western societies.
- “Extra cortical organization of complex mental functions”: all types of human cognitive processes are always formed with support of cultural elements.
- Ability assessment DO NOT CROSS cultures:
  - Values and meanings
  - Modes of knowing
  - And conventions of communication

Cultural Values affecting cognitive-and *any*- testing

- 1- One to one relationship:
  - Specific way to relate with other people
  - Examiner and examinee: aliens
  - Contradicts usual cultural way of living: different people collaborate in diverse activities:
    - *Ex: African Societies*
  - Individual oriented vs. social-group oriented societies

Cultural Values affecting cognitive-and *any*-testing

- 2- Background authority:
  - Implies a subordinate relationship
  - Examiner ‘s authority may not be clear
  - Experience with authority
    - *Ex: Refugee camps*

- 3- Best performance:
  - Most significant in a culture highly valuing competition, but not in a less competitive one
    - *Ex: African societies: emphasis on collaboration and not so much on cognitive testing*

Cultural Values affecting cognitive- and *any*- testing

- 4- Isolated environment:
  - Specific way to relate with other people
  - Isolated room, doors closed, private, intimate situation
  - Quite inappropriate in many cultures.

- 5- Special type of communication:
  - Refers to intimacy-formality dimension
  - Examiner uses stereotyped formal language
    - *Ex: Level of schooling important here as well*

Cultural Values affecting cognitive- and *any*- testing

- 6- Speed:
  - TIME understood differently across different cultures
  - Frequently interpreted as social and cultural construct
  - For many*: speed tests are inappropriate; speed and quality contradictory*
  - Significant differences in attitudes to timed procedures:
    - *Zambia: children performed speeded tasks slower than in the USA.*
    - *In Uganda: slowness of cognitive performance linked to intelligence by villagers in rural areas.*
  - Urbans: better on cognitive testing than in rural areas
  - In USA, differences between African American and whites: acculturation

Cultural Values affecting cognitive- and *any*- testing

- 7- Internal or subjective issues
  - Refers to intimacy/formality dimension
  - What does privacy mean?
    - *Example with Latin patients: sharing minor details of therapist/examiner's lives make them feel more comfortable and welcome*
    - *Vs. asking: "are you feeling depressed" that may be considered inappropriate and invasive*
  - Questions about cognitive issues, may be about internal subjective representations, and very personal an private in some cultures.

Cultural Values affecting cognitive-and *any*- testing

- 8- Use of specific Testing elements and strategies:
  - Physical elements (figures, blocks, pictures..) are culture dependent elements
  - Unfamiliar, or not equally familiar
  - Rationale and procedures used in cognitive testing rely on cultural values that ARE NOT universal values.

Other Cultural, Socioeconomic factors affecting testing

Socioeconomic status

- Poverty level
- Immigration status
- Level of schooling:
  - Skills that promote performance
  - Familiarity with test taking
  - Directly develops cognitive skills
  - Black-White differences attenuated when adjusted for education levels and quality

Examiner's characteristics

- Demographics characteristics of **examiner** play crucial role:

- 1- **Age**: older vs. younger
- 2- **Gender**: match or mismatch
- 3- **Ethnicity**
  - May be the most powerful variable in cognitive testing
    - *Exogroup vs. endogroup*
    - *Mismatch can lead to lower scores on cognitive testing*
    - *Comfort, understanding better directions*
  - Acculturation

Instructions

- Two ways:

1- Standard statements

2- Function is to understand what the test is about: guidelines for examiner and can be worded and adapted.

- Most Latin American neuropsychologists interpret instructions the second way vs. Americans.

- Formal Language: educational level

- May impact test performance

Testing limitations and how to address them

Screening and Diagnostic tools limitations

- Instruments are referenced to local and age norms.
  - Were the norms inclusive of the diversity of families found in the communities where tool will be used?
- Did the 'diverse' children also represent variations within the communities in which the tool will be applied?
  - For example, children within a group may vary in socioeconomic status, languages spoken, immigration status, and diversification
- Does it allow assessment in the child's dominant language?
- Will personnel familiar with the family's culture, practices, and beliefs conduct the assessment?

Screening and Diagnostic tools limitations

- Skills measured: skills that ***this*** child has learned?

- Does the tool distinguish between a developmental or maturational lag, and behaviors that can be brought about by learning.
  - *For example, if a child is unable to spoon-feed, is it because she is neurologically unable to perform the complex movement? Or is it simply because she has not learned that skill and will easily learn it given the opportunity?*

It's more than translation

Do parents understand the screening/diagnostic questions?

- Make sure that phrases captures meaning, ensuring translation did not distort it
- Appropriate examples to clarify culturally specific questions ex: *repeats phrases heard on radio; is this singing? or echolalia*

Consider literacy level, as well as language:

- Interpreters: proficient in the language
- Cultural liaisons: proficient in distinct cultural issues

How to account for cultural factors in testing

- Using mother tongue
- Behavioral scales, more qualitative assessments maybe preferred in non Western societies.
- Culturally most appropriate strategies selected: interpretations, values, behaviors
  - *Ex: Latin Culture: family, greater harmony, respect for authority figures, close interpersonal relationships.*
- Redeveloping cognitive tests with cultural, SES, representations
- Norms for different cultural groups especially for verbal ability tests

How to account for cultural factors in testing

- Sampling strategies accounting for education level, residence (urban vs. rural), poverty level
- Some tests more universal (categorical fluency tests: ex. animal names) vs. culture dependent (interpreting proverbs).
- Language structure
- When assessments are conducted in rural areas, aim to assess competences valued and nurtured by these communities
  - Ex: social responsibility measures in Gambia

How to account for cultural factors in testing

- NON VERBAL COGNITIVE TESTING: thought to be culture free, however:
  - Education++ and residence factors important (AA, Colombian, Finns)
  - Drawing, maps, 3D reconstructions not culturally universal
  - Shapes: Zairian vs. US children
  - Some visual spatial skills may be higher in other cultures:
    - *Ex: Amazonian Indians, Seashore Rhythm Test in Colombian children*
  - Result of complex interaction of brain organization, culture experience and Learning.

How to account for cultural factors in testing

- For Language testing:
- Language similarity and language of schooling contribute to performance on linguistic and metalinguistic tasks by bilingual children.
- Some tests more universal (categorical fluency tests: ex. animal names) vs. culture dependent (interpreting proverbs).
- Development of equivalent tests more than translation
  - Word frequency, equivalence of linguistic constructs
  - Counting systems

4- What about Autism Testing and Culture

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Autism and culture

- *Disability* is a socially and culturally situated construct
- Families of children of diverse cultures may not symptoms of a 'delay' or 'disability'
- Stigma
- **ASD: screening and diagnosis based on behavioral criteria : Inherent cultural factors**
  - **Eye contact, hand movements, echoing: different meanings**
- **Concepts unfamiliar to diverse families.**

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Cultural Variations in an autism phenotype

- Variability in perceptual and cognitive styles.
- Field Dependent: highly influenced by context of a scene; globally biased perceptual style.
- Field Independence: break the field into parts, more locally biased perceptual style.
- Weak Central Coherence (WCC)= Field independence and used in ASD.

Cultural Variations in an autism phenotype

- Individuals from collectivist cultures (East Asian)=
  - Strong central coherence/Field Dependence: Focus on relationships.
- Vs. Individualistic/Western Cultures=
  - WCC: greater focus on objects.
- ASD>> WCC: aberrant brain development, physiological origin.
- Study: Children from England vs. Singapore:
  - WCC only in English children. NOT culturally universal.
  - Perceptual style differences in kids with ASD in western vs. non Western nations.

Assessment of ASD in infants and toddlers

ASD assessment

Measure	Acronym	Age range	Format	Cultural Challenges
Autism Diagnostic Observation Schedule	ADOS	Toddlers to adults	Playbased direct assessment	-Birthday party -Play -New ADOS T: bath -OTHER?
Autism Diagnostic Interview-Revised	ADI-R	Children and adults mental age>2y	Parent Interview	-Parent questionnaire -Skills culturally appropriate -OTHER?

Adaptive behavior

Measure	Acronym	Age Range	Format	Cultural Challenges
Vineland Adaptive Behavior Scales II	VABS II	0 to 90y	Interview or parent rating form	-Language -Skills culturally bound -OTHER? <u>Addressed:</u> 1- using maternal tongue/interpreter 2- Good explanation of skills 3-Opportunities for skills 4- OTHER?
Scales of Independent Behavior Revised	SIB-R	0 to 80+y	Interview or parent rating	
Adaptive Behavior Assessment System-II	ABAS-II	0-89y	Parent, teacher, caregiver rating forms	

Overall development

Measure	Acronym	Age range	Format	Cultural Challenges
Mullen Scales of Early Learning	MESL	0-5;8	Admin.	-Language -Visual receptive skills material -Pictures of objects -Material -OTHER? <u>Addressed:</u> 1- Same ethnicity tester(!) 2-Testing maternal tongue/interpreter 3-Explain instructions 4- OTHER?
Bayley Scales of Infant & Toddler development	Bayley-III	0-7:11	Admin. +quest.	
Battelle developmental inventory	BDI-2	0-7:11	Admin., obs., Interview	
Developmental assessment of young children	DAYC	0-5:11	Admin., obs.quest	

Communication

Measure	Acron-ym	Age range	Format	Cultural Challenges
Communication and symbolic Behavior Scales Developmental Profile	CSBS-DP	6m-6y	Admin., quest.	-Language: parents and child -OTHER? <u>Addressed:</u> 1- Same ethnicity tester 2-Maternal Tongue testing 3-using universal concepts 4- OTHER?
Mac Arthur Bates Communicative development Inventories	CDIs	8-37m	Parent report words/gestures	
Preschool Language Scales-5	PLS-5	0-7:11	Admin.,obs., quest.	
Rossetti Infant-Toddler Language	Rossetti	0-3y	Admin.,obs., quest.	

Autism Screening
Level 1

Measure	Acronym	Age range	Format	Cultural Challenges
Modified Checklist for Autism in Toddlers	MCHAT	16-30m	Parent survey/interview	Language Skills: behavior norms/not encouraged OTHER? <u>Addressed:</u> 1- Interpreter 2-Knowledge of culture perception 3- Other?
Pervasive Developmental Disorders screening test-I & II	PDDST-I	18m-4y		
Ages and Stages Emotional	ASQ:E	6-60m		

Example Screening Test
M-CHAT: Does your child…

- Like to be swung?
- *2) Take interest in other children?*
- Like climbing?
- Enjoy peek-a-boo?
- Ever pretend to talk on the phone?
- *7) Ever use index finger to point to ask? To indicate interest?*
- Play properly with small toys?
- *9) Bring objects to show?*
- Look you in the eye?
- Seem oversensitive to noise?
- Smile in response to you?
- *13) Imitate you?*
- *14) Respond to name?*
- *15) If you point, does he look?*
- Walk?
- Look at things you are?
- Make unusual finger movements near face?
- Act as if deaf?
- Understand what people say?
- Stare at nothing?
- Look at your face to check reaction?

Autism Level 1 Screening Tool
MCHAT: (18-36m)

- **Modified Checklist for Autism in Toddlers (**Robins, Fein, & Barton, 1999)
  - ***23 questions***
  - ***Child fails if 2 critical items are failed OR any 3 items are failed*** → ***RISK/Needs further evaluation***
  - ***Time: 5-10mn***
  - ***Sensitivity/Specificity: 85/93***
  - ***Free : www.firstsigns.org; www.mchatscreen.com***

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M-CHAT

Should follow-up with a structured interview to decrease false positives.

- **Positive Predictive Value (PPV):**
  - **36% for the initial screening**
  - **74% for the screening plus follow-up telephone interview**

- **The M-CHAT Follow-Up Interview can be downloaded free of charge from http://www2.gsu.edu/~psydlr or www.mchatscreen.org**

Robins &Dumont-Mathieu: Dev and Behav pediatrics. April 2006
Robins, 2007

5-Implications for follow-up, referrals, and treatment

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Learn about the families you work with

Each family is unique

- History of their country
  - *Health system, education system*
  - *Demographics: age expectancy; maternal/infant mortality rates; average literacy*
- Were they in refugee camps, did they witness wars?
- Does the word autism exist in their country/language?
- What do they think causes the delays?

Learn about the families you work with

Were they refugees in camps?

Did they witness wars?

Important questions to ask families

What do you know about autism?

What do you think causes autism?

Important questions to ask families

- 1. What do you think caused the problem?
- 2. Why do you think it happened when it did?
- 3. What do you think this problem does to you? How does it work?
- 4. How severe is your child's problem? Will it have a short course?
- 5. What kind of treatment do you think your child should receive?
- 6. What are the most important results you hope to receive from this treatment?
- 7. What are the chief problems your child's problem has caused for you?
- 8. What do you fear most about your child's problem?

- *Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. Annals of Internal Medicine, 88 (2), 251-258.*

Parental beliefs about causes and course of their child's autism

- Parents beliefs about the cause of their child's autism: impact on decisions regarding future health care, family planning, *maternal mental health*.
- No definitive information on cause, course or treatment: *parents come to their interpretation of the disorder*
- Link between beliefs and choice of interventions

Parental beliefs about causes and course of their child's autism

- Review of literature 1995-2009:*Autism, beliefs, culture, parents;* 12 studies identified

- Cultural beliefs as to cause:
  - Those who assumed responsibility were the most stressed (punition of parents 'sins)
  - Those attributed to God's will or fate, less stressed
  - Heredity, stress during pregnancy: distress

Parental beliefs about causes and course of their child's autism

- Other disabilities:
  - Chinese American families: punishment of past violations of religious, ethical, or cultural code as etiology of disability.
  - Traditional Jewish Oriental: Religious or magical causes
  - Cultures in which reincarnation is a belief, disability may be viewed as result of transgression in past life

Parental beliefs about causes and course of their child's autism

- Parents' expectations on course of disorder:
  - Latino culture: "*Fatalismo"; one can do little to alter their fate*
  - Maybe viewed as temporary (Chinese in NY)
- Beliefs affect integration in community:
  - Ultraorthodox Jewish mothers in Israel: responsibility for integration in community whereas others wait for society to change its perspective
  - Chinese: fear Stigma
  - Middle Eastern cultures: Stigma
- Parents mental health:
  - Guilt: perception of contribution to disorder, responsibility for agreeing to immunization, genetic.

Parental beliefs about causes and course of their child's autism

- Link between beliefs and intervention:
  - Latino children with new diagnosis of autism 6x more to receive non traditional treatment strategies.
  - Ethnic minorities: more likely to have explanatory beliefs for mental health disorders different than professional communities, then less likely to seek services.
  - AA less likely to receive diagnosis on first visit
  - Asian Indian families: more likely to notice social difficulties vs. speech delays
  - Haitian Creole may use more non traditional treatments

Practical Tips with diverse families

- Clarify if an Interpreter is needed ***before*** the visit
- Explain testing of young children for early intervention
- Ask:
  - General questions about the child's communication and social skills, and then specific ones.
  - About the family's understanding of and expectations for child development.
  - "What are your concerns about your child?""What do you think is the cause of this problem?"

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Cultural Considerations Around Screening

- Unfamiliar concepts of autism and screening
- Inherent cultural factors in the screening of autism
  - Children's behavior may reflect cultural norms
  - Some behaviors seen as culturally appropriate
- Screening tools may be anxiety provoking, confusing
  - More involved than just translation – more than interpreting language – culture too
  - STIGMA

Examples

- Ask:

"What are your concerns about your child?"

"What do you think is the cause of this problem?"

Express your concern **only after the family's perspective has been shared.**

REMEMBER: families may not see a problem or concern, especially if they are first-time parents.

Use targeted questions about the child's behavior, communication, play, and interactions with other children.

Practical Tips with parents

- **COMMUNICATE SLOWLY AND CLEARLY**
- **CULTURAL LIAISON**
- *It can sometimes take multiple conversations, even several visits, to discuss concerns with families and work towards referral.*

Remember:
More than translation

Do parents understand the screening questions?

- Make sure that phrases captures meaning, ensuring translation did not distort it

- Appropriate examples to clarify culturally specific questions ex: repeats phrases heard on radio; is this singing? or echolalia

Consider literacy level, as well as language:

- Interpreters: proficient in the language
- Cultural liaisons: proficient in distinct cultural issues

Thorough and clear conversations

When screening is failed

When screening is failed

Emphasize that screening identifies only that a child is at higher risk of ASD, but is not a diagnosis.

Be **careful** about using the word “autism ” if families do not ask you about it specifically.

If they do, it is critical to ask:

- “What have you heard about autism?”
- “What does the term “autism” mean to you?”

Reassure: when a young child has delays in talking, interacting, or behavior, there are many things that can help

Providing Diagnosis

- Dialog with families essential to understand:
  - Perceptions, beliefs, priorities
  - Impact of child's disability within their cultural community
  - Choice of interventions

- *Communicate slowly and clearly*
  - Help from interpreter, cultural liaison
  - Several discussions needed sometimes

- "HOW" more important than the "WHAT":
- PATIENCE, COMPASSION: CROSS CULTURAL

Implications for treatment referrals

- Enlist collaboration of interpreters, cultural liaisons, nurses, community agencies, social workers, or others, in supporting the family through this process.
- Identify a person in your practice or community with cultural and linguistic knowledge, as well as professional experience in ASD, to be available to families
- Have printed audio/audio-visual materials available in the families' dominant language
- Connect parents to a network of other parents with similar issues.

Implications for treatment

- Identify goals mutually agreed upon by the interventionist, educators, specialists, *and* the family.
- Include the child's strengths as the foundation.
- Encourage the implementation of multicultural practices which honor and respect every child's culture and language.

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6- Available resources

- Considering Culture kit from MA Act Early team
- Cultural competency resources
- Autism Consortium Parent Information Packet
- *Create Resource list with participants*

How can the state team increase cultural outreach in our work?

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Considering Culture in Autism Screening

Massachusetts Act Early




- AMCHP State Systems Grant
- Culturally competent autism screening guide
- M-CHAT in 5 languages
- Disseminated to 200 members of MA AAP and 55 executive directors of community health centers
- Posted for use in public domain at www.MAActEarly.org

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Visit our Web site online at www.MAActEarly.org

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Greater Boston Community Health Centers

Cultural Liaisons (CL):

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- Haitian Health Institute, Marie K. Foureau
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- Mattapan Community Health Center, Tarma Johnson, RN
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The Process

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Getting Started

- Initial whole group meeting to brainstorm ways to get cultural perspectives in autism screening.
- Ideas:
  - Pediatricians and Parents separate focus groups
  - Surveys of pediatricians
  - Qualitative analyses

Approach

- Most effective way to have insight:
  - Cultural Liaison
  - Pediatricians practices
- Each identified cultural pediatric group and cultural liaison:
  - Stephanie: Vietnamese – Dorchester House
  - Nicole: Haitian Creole – Mattapan CHC
  - Alison: Hispanic – Martha Eliot
  - Roula: Chinese – Tufts Asian Clinic

The interviews

We developed questionnaires

Goal: discuss with PCP and CL's perception, experiences, and what is currently being done.

Meetings with CHC groups:

Nicole: Lunch ,questionnaire with all

Alison: shared questions at grand rounds to pediatricians

Stephanie: cultural liaison & pediatricians

Roula: met with CL then with pediatricians and CL

Cultural Liaisons questions

1- What are the difficulties that families from ……culture might have in recognizing symptoms of autism in toddlers?

2-Do …… families find difficulties answering questions on screening tests for autism? What questions might be difficult to understand (show CL any screening tests used at that clinic)?

3-Are there any specific terms that pediatricians need to use when describing the development (particularly the social emotional development) of children from ……culture?

Cultural Liaisons questions

4- What are terms/concepts that families from ……. background would find hard to understand or are not applicable to the way they raise their child, such as:

*is eye contact encouraged in this culture or not,

*is it appropriate to imitate adults or not.

(May need to go through terms in screening questions specifically with CL.)

5-What can clinicians do to make ASD screening effective with families from …… culture?

Clinicians questions

1- How do you screen children for ASD (including what instruments are used)?

2- How do you communicate screening results and handle referral for evaluation with families?

3-What works well in ASD screening with your non- or limited English language families?

4- What does not work well in ASD screening with your non- or limited English language families?

5- Are there any specific cultural or linguistic considerations that are important when doing ASD screening with your population?

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The follow up

- Nicole translated the MCHAT to the Haitian Creole language
- DBP's met to share information and discuss best presentation of info in useful way to PCP
- Each DBP went back to pediatric group for feedback lunch about information obtained from all sites
- DBP wrote stories with help from CL

Putting It All Together

- Thought carefully about way to present information
- Risk of stereotyping
- Information may not be totally generalizable

Putting It All Together

- Created general themes relevant to screening

- Stories to illustrate cultural background

Other resources

- Autism Consortium:
- Valuable Autism information for parents, translated in Spanish, Portuguese, Khmer, Vietnamese, Chinese. www.Autismconsortium.org
- http://www.autismconsortium.org/take-action/become-a-family-partner/

- National center for Cultural Competence:
- http://nccc.georgetown.edu/

- OTHER RESOURCES *YOU KNOW ABOUT* to ADD?

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The future...

- Continue to promote the kit to pediatricians across MA for use in practice
- Add more family case stories with partners from VT and other states; Current grant pending.
- Workshop completed at the Society Developmental and Behavioral Pediatrics meeting, September 8, 2012
- Paper
- …….

Questions?

Thanks for listening!

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